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Executive summary

Timely access to data during infectious disease outbreaks by those involved in research preparedness and response provides essential input for public health response and for outbreak-related research. This may be clinical, epidemiological and laboratory data, including pathogen genomic sequence data. An additional aspect is the sharing and (international) shipping of samples in situations where local capacities for research are lacking or require more time to develop than is desirable during outbreaks. A multitude of interrelated barriers delay or obstruct timely sharing of data, frustrating efficient public health responses and ultimately the potential use of such resources in innovations. These barriers, typically summarized under the term PEARL (Political, Ethical, Administrative, Regulatory and Logistical), are complex in nature and difficult to circumvent, especially during outbreaks when multiple countries and sectors are involved. This is often the case when dealing with (re-) emerging zoonotic disease outbreaks, since transmission routes are complex, cross-sectorial collaboration is essential, and economic and social issues are usually involved. Barriers and enablers for data sharing may vary depending on priorities and perspectives from stakeholders. While some countries or institutes may perceive data sharing as a way to help others in diagnosing and responding to a biological threat, others who are in lack of the specific capacity might and sometimes do consider it as a form of exploitation or even 'biopiracy'. Under a One Health approach, a wide variety of stakeholders, with competing interests, different priorities, and ownership issues are manifold and need to be understood, to promote accessible and timely sharing of data as a key component of outbreak preparedness for (re-)emerging disease outbreaks.

Therefore, historical analyses of data sharing practices during past epidemic outbreaks that involved a wide variety of stakeholders were commissioned by the Wellcome Trust and The Department for International Development (DFID) of the UK. Collectively, these aim to provide an overview of critical lessons learned from past experiences and to support the development of sustainable data sharing practices for future research and infectious disease outbreak preparedness. This case study focused on outbreaks of MERS Coronavirus (MERS-CoV), as a new emerging zoonotic pathogen without a licensed intervention, to provide an in-depth understanding of barriers and enablers to data sharing to such zoonotic emerging infectious disease (EID) outbreaks.

Background on the Middle East Respiratory Syndrome (MERS) epidemic: a public health emergency of international concern?

The MERS epidemic started in 2012, caused by a newly emerging coronavirus, MERS-CoV. To date, 2,266 confirmed cases from 27 countries and 804 MERS-CoV associated deaths have occurred, according to the WHO. Although the disease has a zoonotic origin, large health care facility related outbreaks (e.g. hospital outbreaks) occurred in Saudi Arabia, the United Arab Emirates and the Republic of Korea. Camels were identified as an (asymptomatic) reservoir for MERS-CoV and as a potential source of human infections. How this transmission occurs, however, is not fully understood. As shown by the occurrence of 45 new cases of MERS in the past six months, including 14 deaths, MERS-CoV constitutes a constant public health threat. This threat is especially prominent in the Arabian Peninsula, where new introductions of the virus into the human population continuously take place and could potentially lead to further spread.

To address this threat, the timely and effective sharing of clinical, epidemiological and laboratory data, including pathogen genomic sequences is considered essential. The overall goal of the current study therefore is to improve global preparedness to infectious diseases outbreaks of public health concern by providing an in-depth understanding of barriers and enablers to sharing of clinical, epidemiological and

laboratory data, including pathogen genomic sequences, during the MERS-CoV epidemic, and by studying how data shaped research and public health responses to this outbreak.

Scope

The current study focused on the sharing of clinical, epidemiological, and laboratory data as part of the clinical and laboratory research preparedness and response to infectious disease outbreaks. In terms of MERS-CoV outbreaks, this case study focused on primary transmissions at the animal –human interface in Qatar, while also reflecting on the perspective from stakeholders from the wider region of the Arabian Peninsula. Hospital acquired infections were outside the scope of this case study. This case study considered different levels of data sharing representing the flow of data between stakeholders at different levels:

i)   National, where data is shared among stakeholders within Qatar and is used to monitor population health, target response, and resource allocation,

ii)   Regional, where data is shared among countries in the same region, or a group of countries with a collaborating institute or organization,

iii)   International, where data is shared among countries and organizations outside the region, including research centers, and

iv)   Global, where data is shared among international agencies, and inter-agency levels, and is used to estimate the global burden of disease and to contain emerging global health threats.

Methodology

The methodology used is in line with previous research on the topic of data sharing (Ribeiro et al., 2018). A comprehensive desk study was performed using 144 sources of white and grey literature, meeting- and press reports. This was used to reconstruct a detailed timeline of the MERS-CoV epidemic and the outbreak response including the flow of data as described in literature. Key stakeholders relevant to the response were identified from this map and 70 stakeholders were invited to participate. In total, 42 stakeholders participated in data collection (response rate 60%) including governmental representatives, public health experts, epidemiologists, clinicians, veterinarians, virologists, and social scientists. These stakeholders originated from public health or animal health institutes, academic research institutes, or supranational organizations. Combined, these stakeholders provided expertise relevant for all levels of data sharing (global, international, regional and national). From these participants, 27 key stakeholders were interviewed face-to-face or by phone. The semi-structured interviews followed a standardized interview guide. Additionally, 15 key stakeholders participated in a stakeholder workshop, divided into three groups for expert group discussions. The group discussions were performed according to a standardized format (1.5 hours in duration). From these interviews and workshops, a team of researchers inductively derived barriers and enablers to data sharing via thematic analysis. A root-cause analysis was performed to identify causal relations between barriers. Preliminary results were discussed with members of the study team, revised and used as input for this summary report.

Barriers and enablers to data sharing

The current research identified a list of 8 distinct barriers that were highly interconnected. Additionally, 18 distinct but interrelated enablers were identified. These barriers and enables were grouped into four categories:

i) Inclusive collaborations for global health, reflecting on collaborations between stakeholders across sectors, across different levels of data sharing and in a One Health approach

ii) Legal framework and authorization process, reflecting on regulations, guidelines and policies in relation to data sharing as well as the authority of stakeholders to decide on data sharing

iii) Ownership rights and interests of stakeholders in the assignment of ownership rights over data, as well as governance over its use

iv) Practical aspects of data collection, production and release, related to technical capability and capacity to generate and share data

While some topics were indisputable enablers to data sharing, others were identified as enablers in some circumstances, but also potential barriers when used or interpreted differently; such enablers were designated as situational enablers. Notable is the interconnection of these barriers at the different levels of interaction that were mentioned, indicating that the delay of data flow at one level affects the flow of data at or to another level. For example, the delays in notification channels and case definitions for animals at the global level affected the quality and completeness of data shared from a national level to the international and the global level.

Lessons learned and recommendations

Six main lessons were drawn from the stakeholders' experiences, and enablers and barriers. First, the importance of building and maintaining trust between sharing parties, based on a respectful collaboration, whether or not formalized through agreements governing data sharing. Second, the importance of bilateral data sharing and reciprocity of data sharing for sharing parties. The reciprocity of data sharing should be reflected in, amongst others, the assignment of ownership rights over data, in fair recognition of contribution to publications coming out of the data, and in capacity building. Third, the importance of inclusive inter-sectoral and One Health collaboration, based on a pre-organized stakeholder engagement with pre-defined roles and responsibilities of the stakeholders involved. Fourth, the need for the creation of a One Health preparedness and response system that fits all zoonotic EIDs with appropriate supportive technical infrastructure as well as pre-defined access rights and responsibilities of stakeholders. Fifth, the importance of having trusted international collaborating partners as external advisor and reference centers. Such international support for outbreak response is not only essential for low-capacity countries but all countries, which do not always have the expertise and experience for dealing with unknown or unexpected EIDs. Finally, barriers are highly interconnected in a multi-layered system of sharing, and therefore complex to solve. Therefore, addressing these barriers requires solutions that take into account the complexity and multitude of root causes that cause these barriers as well as how these barriers are reflecting upon each other on global, international and national levels of data sharing.

These main lessons learned provided the basis for the recommendations, which were categorized in recommendations to i) improve capacity and training, ii) create pre-established infrastructure and systems for data sharing, and iii) capitalize and build forward on pre-established collaborations based on trust and fairness of sharing.

Conclusion

The swift and transparent sharing of (confidential) data is a crucial pillar of outbreak response. This in-depth study of barriers and enablers to data sharing during the emergence of MERS-CoV provided

important insights that can be used to strengthen preparedness to zoonotic diseases, including the "Disease X" scenario listed a key priority by the WHO.

Introduction

Timely access to data during infectious disease outbreaks by those involved in research preparedness and response provides essential input for public health response and for outbreak-related research. This may be clinical, epidemiological and laboratory data, including pathogen genomic sequence data. An additional aspect is the sharing and (international) shipping of samples in situations where local capacities for research are lacking or require more time to develop than is desirable during outbreaks. A multitude of interrelated barriers delay or obstruct timely sharing of data, frustrating efficient public health responses and ultimately the potential use of such resources in innovations. These barriers, typically summarized under the term PEARL (Political, Ethical, Administrative, Regulatory and Logistical), are complex in nature and difficult to circumvent, especially during outbreaks when multiple countries and sectors are involved. This is often the case when dealing with (re-) emerging zoonotic disease outbreaks, since transmission routes are complex, cross-sectorial collaboration is essential, and economic and social issues are usually involved. Barriers and enablers for data sharing may vary depending on priorities and perspectives from stakeholders. While some countries or institutes may perceive data sharing as a way to help others in diagnosing and responding to a biological threat, others who are in lack of the specific capacity might and sometimes do consider it as a form of exploitation or even 'biopiracy'. Under a One Health approach, a wide variety of stakeholders, with competing interests, different priorities, and ownership issues are manifold and need to be understood, to promote accessible and timely sharing of data as a key component of outbreak preparedness for (re-)emerging disease outbreaks.

Therefore, historical analyses of data sharing practices during past epidemic outbreaks that involved a wide variety of stakeholders were commissioned by the Wellcome Trust and The Department for International Development (DFID) of the UK. Collectively, these aim to provide an overview of critical lessons learned from past experiences and to support the development of sustainable data sharing practices for future research and infectious disease outbreak preparedness. This case study focused on outbreaks of MERS Coronavirus (MERS-CoV), as a new emerging zoonotic pathogen without a licensed intervention, to provide an in-depth understanding of barriers and enablers to data sharing to such zoonotic emerging infectious disease (EID) outbreaks.

Background on the MERS epidemic: a public health emergency of international concern?

The MERS epidemic started in 2012, caused by a newly emerging coronavirus, MERS-CoV.[1] To date, 2,266 confirmed cases from 27 countries and 804 MERS-CoV associated deaths have occurred.[2] Although the disease has a zoonotic origin, large outbreaks occurred in Saudi Arabia, the United Arab Emirates and the Republic of Korea, associated to health care facilities (e.g. hospital outbreaks). Camels were identified as an (asymptomatic) reservoir for MERS-CoV and as potential source of human infections.[3] However, how this transmission occurs is not fully understood. MERS-CoV constitutes a constant public health threat, especially in the Arabian Peninsula, where new introductions of the virus

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[1] Zaki AM, van Boheemen S, Besteboer TM, Osterhaus ADME, Fouchier RAM. Isolation of a Novel Coronavirus from a man with pneumonia in Saudi Arabia. New England Journal of Medicine, 367(19), 1814-1820.

[2] WHO Update on MERS-CoV situation, 27 November 2018. https://www.who.int/emergencies/mers-cov/en/ Accessed 30 November 2018.

[3] Reusken CB, Haagmans BL, Muller MA, et al. Middle East respiratory syndrome coronavirus neutralizing serum antibodies in dromedary camels: a comparative serological study. Lancet Infect Dis 2013 Aug 8

into the human population continuously take place and could potentially lead to further spread. For example, in the past six months 45 cases of MERS have been reported, including 14 deaths.

The overall goal of the study is to improve global preparedness to respond to infectious diseases outbreaks of public health concern by providing an in-depth understanding of barriers and enablers to sharing of clinical, epidemiological and laboratory data, including pathogen genomic sequences, during the MERS-CoV epidemic, and by studying how data shaped research and public health responses to this outbreak.

Scope

The study focused on the sharing of clinical, epidemiological, and laboratory data as part of the clinical and laboratory research preparedness and response to infectious disease outbreaks. This scope encompasses outbreak research involving:

- x Epidemiological investigation and surveillance: tracking of cases and contacts, outbreak investigation, including identification of sources and transmission modes;
- x Clinical research: research involving a substantial amount of work related to the observation of, data collection from, or diagnostic or therapeutic intervention on multiple or individual patients;
- x Laboratory research: research involving all activities concerning laboratory outbreak response and research, including the sharing of microbial genetic resources, i.e. strains and genetic sequence data from pathogens and related metadata, samples, assays, protocols, and experiences.

In terms of MERS-CoV outbreaks, this case study focused on primary transmissions at the animal-human interface in Qatar, while also reflecting on the perspective from stakeholders from the wider region of the Arabian Peninsula. Thereby hospital acquired infections were outside the scope of this case study. This case study considered different levels of data sharing representing the flow of data between stakeholders at different levels, based on previous research describing different levels of data sharing generating corresponding different benefits[4]:

- i)   National, where data is shared among stakeholders within Qatar and is used to monitor population health, target response, and resource allocation,
- ii)   Regional, where data is shared among countries in the same region, or a group of countries with a collaborating institute or organization,
- iii) International, where data is shared among countries and organizations outside the region, including research centers, and
- iv)   Global, where data is shared among international agencies, and inter-agency levels, and is used to estimate the global burden of disease and to contain emerging global health threats.

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[4] Van Panhuis W, Proma P, Emerson C, Grefenstette J, Wilder R, Herbst A, Heymann D, Burke D. A systematic review of barriers to data sharing in public health. BMC public health 2014, 14(1), 1144

Methodology

The methodology used is in line with previous research on the topic of data sharing [5]. A comprehensive desk study was performed using 144 sources of white and grey literature, meeting- and press reports (See Annex I). This was used to reconstruct a detailed timeline of the MERS-CoV epidemic and on the outbreak response including the flow of data as described in literature (See Annex III). Although the scope of this study is MERS CoV outbreaks at the animal—human interface in Qatar, a broader consideration of events related to outbreaks in an international context was considered for a complete overview and understanding of relevant events and their co-relations, from the diseases emergence (patient "zero") until our current time. This activity resulted in a provisional overview of the actual course of events/facts and stakeholders involved, which was additionally used to make an individualized summary of contributions in preparation of the interviews, still with gaps and uncertainties that were filled in and checked during the interviews. Key stakeholders relevant to the response were identified from this map and 70 stakeholders were invited to participate through various approaches including the personal networks, emails or phone calls as appropriate to their culture and context. The invitation included information about the study design, aims, expected time investment and other practical arrangements (e.g. confidentiality and informed consent).

The following inclusion criteria were applied:
- x Work of stakeholder is/was related to MERS-CoV public health response or related research during the outbreaks
- x Stakeholder has/had authority to make (a) decision(s) on data sharing or a key role in or key influence on data sharing within their level of data sharing (national, regional, international, global)
- x Stakeholder is/was collaborating and sharing data with stakeholders from Qatar
- x Stakeholder is/was involved in laboratory or public health research that directly or indirectly shaped the public health response in Qatar
- x Stakeholder was involved in crucial phases of the timeline for public health response and outbreak related research

In addition, the following stakeholder exclusion criteria were applied:
- x Stakeholder does not agree to participate
- x Stakeholder is unavailable during time frame of data collection of this case study
- x Stakeholder feels he/she has not much to say or has insufficient knowledge about the topic of the case study and/or refers to others for answering to case study interview questions
- x Stakeholder is part of the case study team

In total, 42 stakeholders participated (response rate 60%) including governmental representatives, public health experts, epidemiologists, clinicians, veterinarians, virologists, and social scientists from: public health or animal health institutes, academic research institutes, or supranational organizations (See Figure 1). Combined, these stakeholders provided expertise relevant for all levels of data sharing (global, international, regional and national). However, the underrepresentation of stakeholders from the regional level of data sharing should be noted as a limitation, due to a lack of response and unavailability to participate within the timeframe of our case study. From the participants, 27 key

[5] Ribeiro C, van Roode M, Haringhuizen G, Koopmans M, Claassen E, van de Burgwal L. How ownership right over microorganisms affect infectious disease control and innovation: A root-cause analysis of barriers to data sharing as experienced by key stakeholders. PLoS One 2018; 13(5)

stakeholders were interviewed face-to-face or by phone. The semi-structured interviews lasted at minimum 36 minutes and at maximum 78 minutes, and followed a standardized interview guide (See Annex II). The questions were designed to address six overarching topics: the stakeholder's role and contribution on the MERS-CoV research and response; the stakeholder's knowledge and/or perceptions on the data sharing practices that took place; how these data was applied in the public health research and response; the stakeholder's knowledge and/or perceptions on enablers and barriers to data sharing; and finally possible lessons learned and recommendations for future outbreaks. The informed consent procedure included permission to record the interviews and to use the anonymized data in further publications. The interviews were recorded, transcribed, and coded to ensure anonymity of the stakeholders. Additionally, 15 key stakeholders participated in a stakeholder workshop, divided into three groups for expert groups discussions. The group discussions were performed according to a standardized format (1.5 hours in duration), and aimed to gather feedback from national stakeholders on the interim case study results. The stakeholders discussed the results in light of the (anonymized) overall viewpoints and experiences of other stakeholders, thereby aiming to converge towards a common understanding of enablers and barriers and decisions on actions to improve data sharing.

Figure 1 Stakeholders response rate was 60%. Stakeholders represented different sectors, levels of data sharing, and domains reflecting their main area of expertise (left table). Right table shows representation of stakeholders who were individually interviewed (top) or participated in the expert group discussions (bottom).

The data collected from the variety of data sources (literature review, workshop and interviews) were thematically analyzed. To this end, a code book was developed that allowed us to quickly retrieve and compare information across data sources on key aspects. The code book was developed iteratively, allowing for the emergence of new themes as the analysis progresses, but initially the code book was developed around key aspects of data sharing as described in literature (timeliness, quality, authorization, equity, etc.). For the data analysis, five predetermined steps were followed: familiarization, identifying the thematic framework, data indexing, data charting, data mapping, and data interpretation.[6] The reconstruction of interpretative frames technique was used to get acquainted with the stakeholders' perceptions and interests on data sharing during the MERS-CoV outbreak, and

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[6] Ritchie J, Spencer L. Qualitative data analysis for applied policy research. The qualitative researcher's companion. 2002; 573, 303-329

enablers and barriers.[7] A root cause analysis was performed to identify causal relations between barriers (Ribeiro et al., 2018). Finally, all findings were brought together to appropriately contextualize them. A cross-cutting analysis devoted specifically to integration and interpretation of our observations was performed, and included a gap-overlap analysis to highlight where the findings reinforce and/or contradict each other. Based on a secondary analysis of the study data, reasons for any discrepancies were analyzed and synthesized. This enabled us to highlight critical lessons learned from past experiences and to support the development of recommendations for sustainable data sharing practices during future research and responses to (re-)emerging disease outbreaks. To this end, iterative discussions were held with the researchers who principally collected and analyzed the data, followed by discussion of the preliminary results in a video conference with members of the study team. Final results were revised and used as input for this summary report.

<div style="border:1px solid black; padding:10px;">
This case study has received ethical approval from Erasmus MC Medical Ethical Committee (approval reference number MEC-2018-1365).
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[7] Grin J and van de Graaf H. Technology assessment as learning. Science, Technology and Human Values 1996, 20(1), 72-99

Data sharing practices during the MERS-CoV epidemic

Before a comprehensive description of barriers and enablers to data sharing that were experienced by the study participants was provided, data sharing practices were revealed that were used by the study participants to share data during the MERS-CoV epidemic to understand the definition of key data in the context of the epidemic according to the study participants and to what extent data sharing occurred during the epidemic.

Types of data

The types of data study participants mentioned to have shared that they felt were crucial for the outbreak/public health response or for outbreak related research are listed below. These types of data were categorized into three categories based on different considerations for data sharing in public health emergences in each of the categories, using the WHO policy statement on data sharing in the context of public health emergencies as guidance document.[8]

1. Data related to and/or necessary for outbreak surveillance, epidemiology and emergency public health response
   x Epidemiological investigation data – human:
      o Confirmed case notifications
      o Suspected case notifications
      o List of confirmed human cases per country
      o Epidemiological evidence of human-to-human transmission (contact tracing)
      o Suspected and/or confirmed sources (exposures) related to human cases
      o Risk factors for acquiring infection
      o History of travel of cases
   x Epidemiological investigation data – animal:
      o Confirmed notifications of infection (sero-positivity)
   x Laboratory/ clinical diagnostic data
      o Case definitions of infections, i.e. diagnostic analyses of samples
      o Diagnostics kits, assays and related materials (e.g. antibodies and reagents) for use
      o Serological data from surveys to assess the extent of the outbreak
   x Information related to epidemiological investigation and surveillance as part of the public health response
      o WHO guidelines for surveillance, case definition and laboratory testing, case investigation, and infection control
      o Reports on IHR notifications
      o OIE guidelines for case definition
      o Clinical guidelines for treatment of cases
      o Scientific/ evidence based protocols for sampling and diagnosis
      o (National) outbreak response plan/ strategies used, and level of preparedness
      o WHO guidelines on the laboratory safety
      o Global risk assessment and trends, and interpretation of shared sequences

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[8] WHO Policy Statement on Data Sharing by the World Health Organization in the Context of Public Health Emergencies, 13 April 201, available online via www.who.int

2. Genetic sequences and biological samples
    o Pathogen genomic data (sequence data)
    o Pathogen genomic data (virus)
    o Samples from patients and/or suspected cases
    o Samples from animals (mainly camels)

3. Data related to/ necessary for outbreak related research
  x Clinical/ epidemiology research data –human:
    o Patient statistics (related metadata): sex, age, disease history and comorbidities, demographics and place of residence at time of start symptoms (if not considered confidential data), date of sampling, type of sample
    o Clinical observational data: description of the case, status of the case, date of onset, date of hospitalization and lab testing, natural history of disease and clinical presentation (clinical course of infection, including disease symptoms and disease outcome)
  x Epidemiology research data –animals:
    o Epidemiological observational data and statistics: age, place and country of origin, location of sampling, date of sampling, type of sample, natural history of infection (if any), husbandry practices, animal movement (trade and market information)
  x Laboratory research data
    o Novel diagnostics for both human and animal populations and related materials (e.g. reagents) for use
    o Culture systems for the virus
    o Guidelines on and cross-validation of diagnostics (already in use and in development)
    o Data on pathogen and transmission: source attribution (main animal reservoir and source of zoonotic transmission to humans), dynamics of transmission events (e.g. routes of exposure), geographic distribution, circulation of virus in human population (sero-prevalence), circulation of virus in animal population (sero-prevalence), virus isolation data, viral evolution and genotypic correlates of viral sequences
    o Data on pathogen-host interaction: viral tropism, receptor data
    o Relevant (small) animal model experiments

Data sharing mechanisms

The following commonly used mechanisms of data sharing were used by the study participants to share data during the MERS-CoV epidemic. These included formal and informal mechanisms for data sharing. The mechanisms were divided into open access sharing mechanisms and closed access sharing mechanisms.

  x Open access sharing mechanisms
    o Open access databases (GenBank)
    o International scientific meetings (semi open access)
    o Scientific publications and supplementary material in journals
    o Countries and institutional websites
    o Public/online notifications, guidelines and reports (ProMed, WHO and OIE meeting reports and online updates, e.g. Disease Outbreak News, DON)
    o Press conferences, press releases (media)

- x Closed access sharing mechanisms
  - o Countries internal public health databases and surveillance systems
  - o Closed consortia:
    - ƒ Research field investigation teams/ missions
    - ƒ European Commission funded consortia
  - o Informal professional networks
  - o WHO (technical) meetings
  - o Confidential communication through calls, e-mails and face-to-face
    - ƒ WHO teleconferences
  - o Notifications to WHO and OIE, through countries animal and public health authorities, including IHR focal points
  - o Notifications to ECDC through IWRS system
  - o IHR Event Information Site (EIS, closed database for Members States' IHR focal points)

Barriers and enablers to data sharing

This case study identified a list of barriers and enablers, grouped into four categories: i) inclusive collaborations for global health, reflecting on collaborations between stakeholders across sectors, across different levels of data sharing and in a One Health approach, ii) legal framework and authorization process, reflecting on regulations, guidelines and policies in relation to data sharing as well as the authority of stakeholders to make decisions on data sharing, iii) ownership rights and interests of stakeholders in the assignment of ownership rights over data and its use, as well as its governance, and iv) practical aspects of data collection, production and release, related to technical capability and capacity to generate and share data (Figure 2). Some of the observed categories were identified as enablers in some circumstances, but also potential barriers when used or interpreted differently, and designated as situational enablers. Each category is discussed in more detail in the sections below.
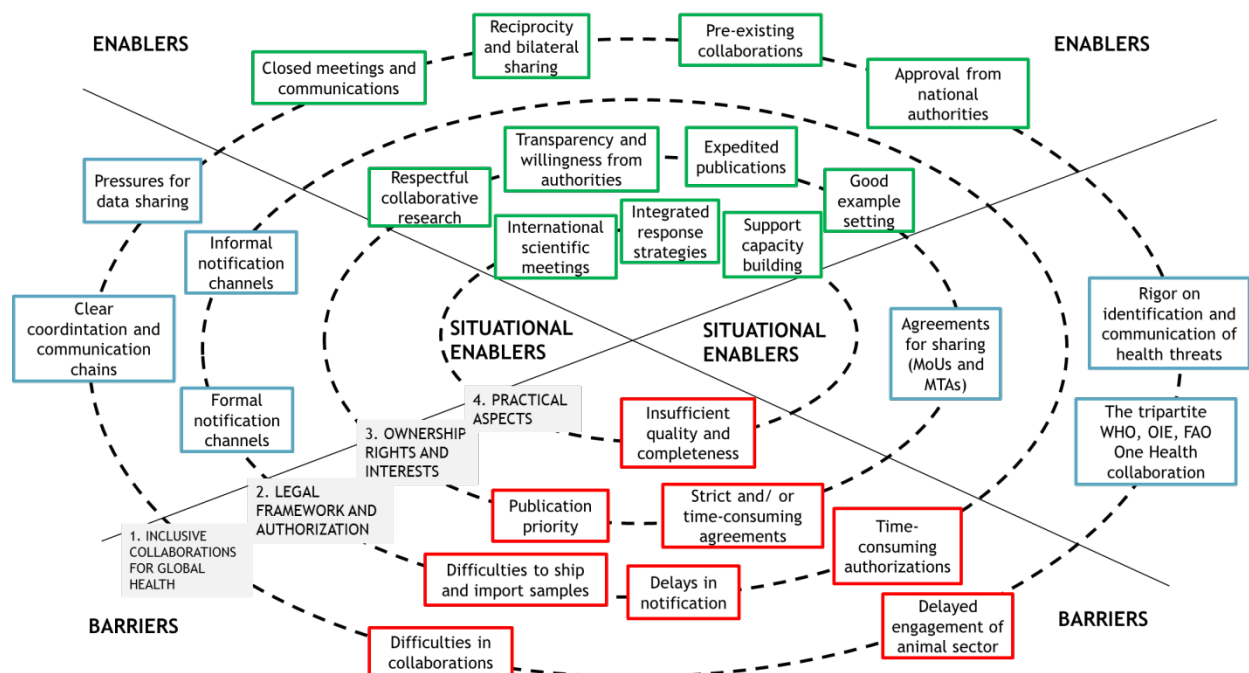

Figure 2. Overview of barriers and enablers of data sharing grouped into 4 main categories (indicated as dashed circles with numbered grey textboxes). Some enablers were context dependent to either facilitate or hamper data sharing, shown in blue as situational enablers. Red topics represent barriers and green topics represent indisputable enablers.

Barriers to data sharing

The study participants mentioned many barriers that either hampered or delayed data sharing during the MERS epidemic. The root cause analysis defined 8 distinct barriers that were highly interconnected as shown by the connection of causes and root causes for distinct barriers (Figures 3 - 6). The figures were drafted based on the arguments provided from the stakeholder interviews and workshops. For instance, some stakeholders mentioned that the deeply rooted cultural importance of camels (Figure 3, right column) led to debate on the credibility of camels as a reservoir (argument column, top), but also the need for confirmatory testing as camels were asymptomatic (argument column, second argument).

Inclusive collaborations for global health (outer circle no. 1, Figure 2)

Two barriers were related to inclusive collaborations for global health for their causal analysis. These are delayed engagement of the animal sector and the difficulties in multi-sectoral collaboration between public health, animal health and research institutes (academia) and One Health collaboration. Root causes related to cultural, social and economic importance of camels, different interests and priorities of stakeholders as well as the observation that pre-established collaborations between stakeholders were not of not sufficiently defined to deal with zoonotic EID outbreaks (Figure 3).
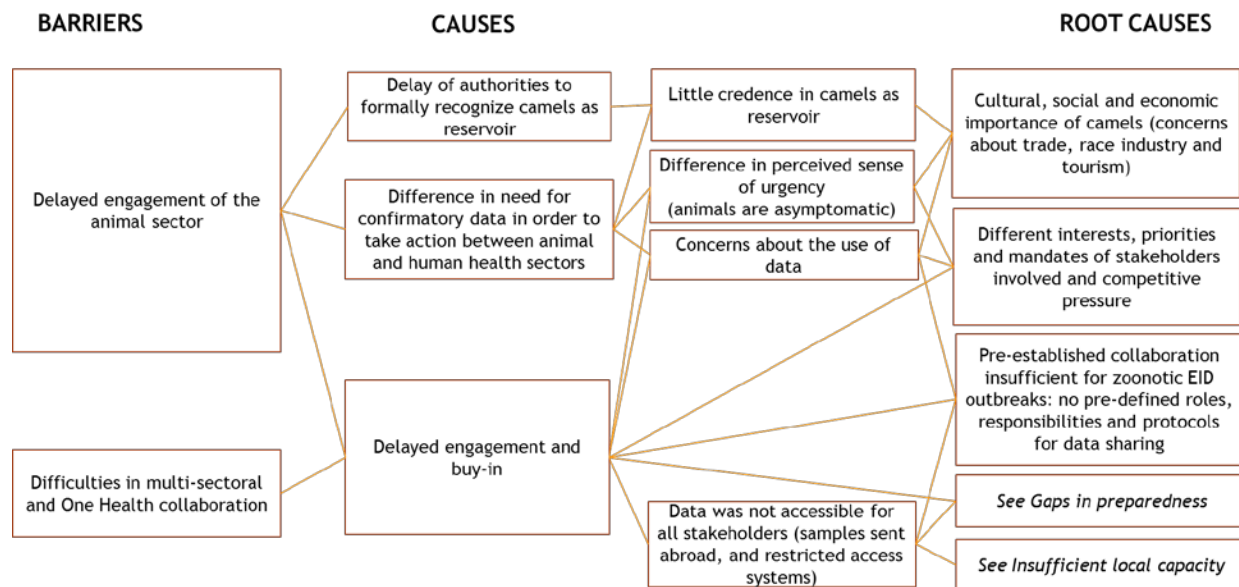

Figure 3 Causal analysis of the two barriers related to inclusive collaborations for global health. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

Legal framework and authorization process (circle no. 2, Figure 2)

This barrier category is composed of three distinct barriers reflecting delays in notification of MERS-CoV infections, time-consuming process to obtain authorization to share data, and difficulties to ship and import samples (see figure 4). Some of the causes and root causes originated from other barrier types, such as inclusive collaborations for global health and practical aspects of data collection, production and release.

Ownership rights and interests (circle no. 3, Figure 2)

The last category of barriers relates to ownership rights and interests and constitutes of two barriers, strict and/or time-consuming agreements that limit data sharing and the importance of priority in scientific publication (see figure 5). Most of the root causes underlying these two barriers related to the uncertainty and lack of control over the use of data once it is shared.

Practical aspects of data collection, production and release (Inner circle no. 4, Figure 2)

The barrier that related to practical aspects of data collection, production and release was the insufficient quality and completeness of data (Figure 6). Most root causes related to gaps in the preparedness for dealing with zoonotic EID outbreaks either at the human-animal interface, at a technical level (e.g. laboratory capacity) or at a cultural level.
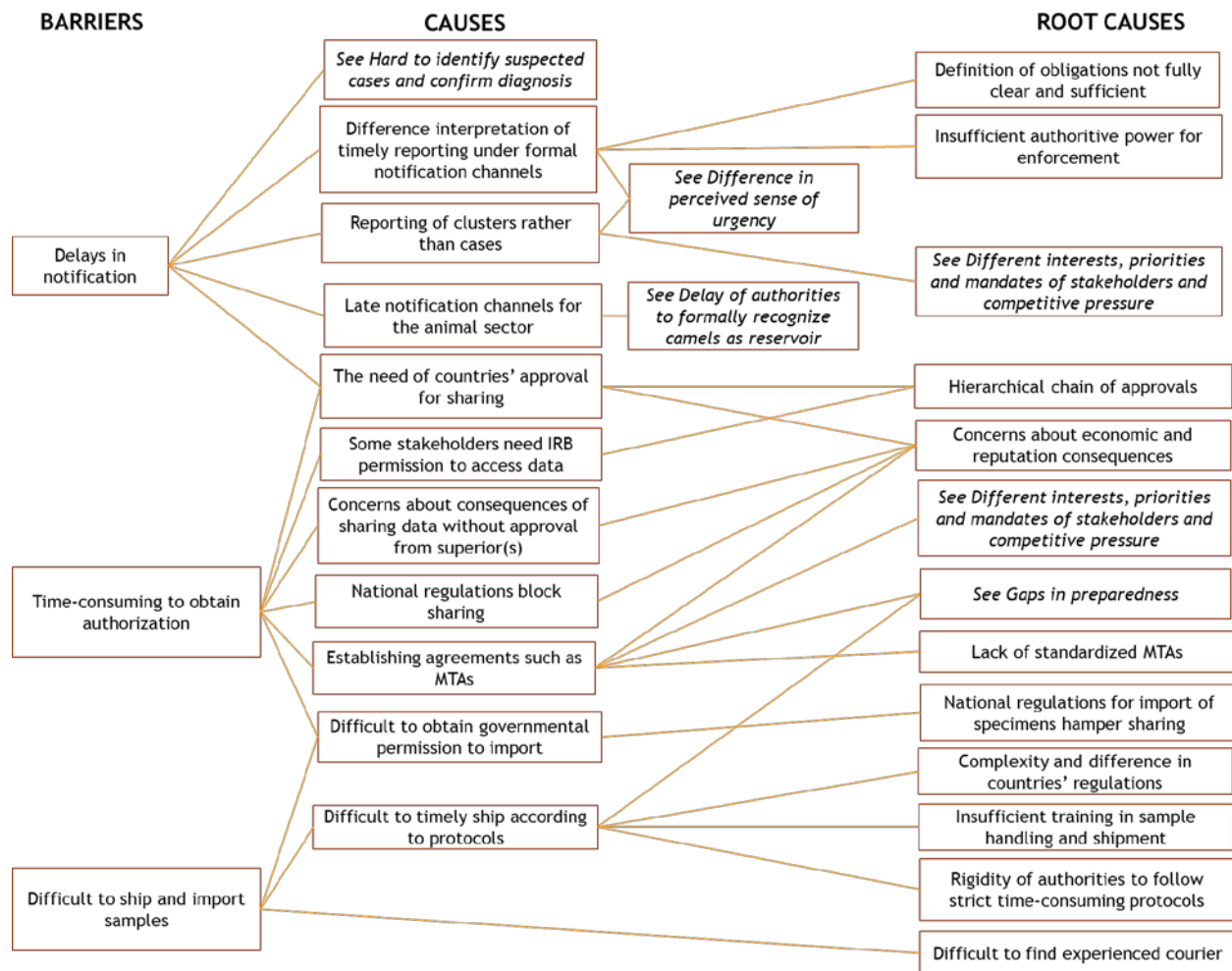
Figure 4 Causal analysis of the three barriers related to legal framework and authorization process. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.
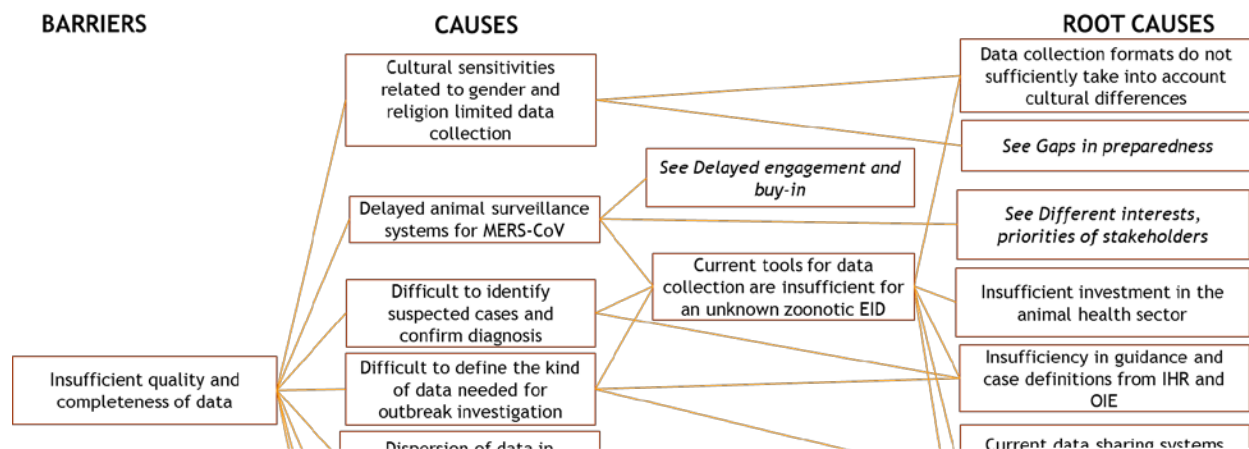
BARRIERS	CAUSES		ROOT CAUSES

Figure 6 Causal analysis of barrier related to practical aspects of data collection, production and use. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

Figure 5 Causal analysis of the two barriers related to ownership rights and interests. Left column represent the two barriers, second column from the left the causes, third column key arguments from study participants explaining relation of some causes to root causes, and right column the root causes, where lines indicate the causal argumentation of the study participants.

Data sharing in public health emergencies: Analysis of barriers and enablers from an outbreak response perspective (SHARE)

The case of Middle East Respiratory Syndrome (MERS)

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Case study report

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